Improving Access to Social and Economic Services for People with Disability in Lao PDR

POLICY RESEARCH REPORT

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Executive Summary

This report draws on the findings of the ADRAS-funded research project: *Improving access to social and economic services for people with disability in Lao PDR* (2014-17). This participatory action research project collected information in three Provinces (Vientiane Province, Savannakhet and Sayaboury) and the Vientiane Capital about the barriers and facilitators to health, education and employment for people with disability. The findings were presented at an interactive workshop in September 2016, and a synthesised analysis of the research findings is presented here. Its purpose is to assist Ministries and Disabled People's Organisations (DPOs) in designing and implementing disability-inclusive policies and programs in Lao PDR.

- The Government of Lao PDR has made a significant commitment to protecting the rights and interests of people with disability with the Decree on the Rights of Persons with Disability 2014. Progress continues towards enacting this as law.
- A commitment to disability-inclusive development requires good disability information – incorporating both medical and social factors such as: nature and level of impairment, gender, ethnicity, rural-urban, rural-remote, and age. This information needs to be collected in a systematic way, be disaggregated and made publicly available.
- Understandings of the multiple disadvantages associated with disability are limited (such as gender, ethnicity, remoteness, multiple disability and high support needs).
- Although the National Committee for Disabled and Elderly (NCDE) holds responsibility for coordination of government services, there are significant barriers to be overcome. These include basic infrastructure such as inaccessible roads, buildings and toilets, and also conflicting policies and information about services and the nature of disability.
- The cost of accessing health services is a significant barrier. Free health insurance, health checks and access to assistive devices are recommended for people with disability.
- Stigma associated with disability is a barrier to citizen participation, and leads to the exclusion of people with disability and an underestimation of the roles they can hold.
- Strengthening the leadership capacity in the disability sector is crucial for disability-inclusive development. The DPOs need to be strengthened so that they can take on more advocacy and education roles at each level of government and in services.
- Sharing information between organisations, such as, information about certain health conditions, barriers to participation, information about new or mobile services, and information about the capacity of people with disability, enhances coordination and service integration.
- Inclusion of a focus on disability in mass organisations, such as the Lao Women's Union and the Lao Youth Revolutionary Union, as well as the private sector, are strongly recommended as a means of progressing disability-inclusive development and improving coordination.
- Service integration leads to a better balance of responsibilities between Central, Provincial and District governments, improved national and local community coordination, greater local autonomy and access to local community knowledge, skills and networks.
- Good coordination requires a legal and administrative framework, organisational planning and procedures, and the involvement of community, family and individuals. People with disability should be represented in each of these components.
- International non-government organisations (INGOs) provide invaluable support to disability-inclusive development in Lao PDR. Improved coordination between INGOs would avoid overlap.

Introduction

This research project, *Improving access to economic and social services through disability-inclusive development in Lao PDR,* was funded through the Australian Development Research Awards Scheme (ADRAS), an Australian Aid initiative of the Australian Department for Foreign Affairs and Trade. The Australian Government focused its aid program with the *Development for All: Towards a Disability-Inclusive Australian Aid Program 2009-2014*, reflecting the Government's commitment to promoting the dignity and well-being of people with disability. The *Development for All Strategy* followed extensive consultation which revealed a "lack of coordination and quality data, large gaps in service provision, high levels of stigma and a lack of understanding of the 'lived realities' facing people with disability" (Australian Government, 2008). That strategy was extended in the *Development for All 2015-2020 Strategy for strengthening disability-inclusive development in Australia's aid program* (Australian Government, 2015).

The research was conducted by a team of researchers from Curtin University (Perth, Western Australia) working together with the Lao Disabled People's Association (LDPA). A memorandum of understanding was formed between Curtin University and the Ministry of Labour and Social Welfare (MOLSW), supported by an implementing partner agreement between LDPA and Curtin University. The project was guided by a Reference Group of key Lao disability stakeholders who met regularly throughout the project.

The research team worked with Lao organisations, government, DPOs, and INGOs, to contribute empirical evidence of barriers and facilitators to social and economic participation and development for people with disability in Lao PDR. The research aimed to improve the quality of information about people living with disability, and to assist relevant Lao government Ministries to develop disability-inclusive development policies and programs to improve social and economic participation for Lao people with disability. The project objectives were:

- To work with key stakeholders in Lao PDR to identify barriers and facilitators to social and economic participation for people with disability.
- To build the capacity of local stakeholders in research, monitoring and evaluation (M&E), and good practice for disability-inclusive development.
- To share research findings, which will support relevant ministries and DPOs' work in designing and implementing disability-inclusive development policies and programs.

The Report is structured as a summary of research findings and policy recommendations under four main headings: Disability-Inclusive Development, Integration and Rehabilitation Support, Capacity Building, and Coordination and Service Integration. The policy recommendations in this Report are based on a combination of findings from this research project and feedback from the September 2016 workshop.

Background

Regardless of context, people with disability are among the most vulnerable in the world. When compared to people without disability, they have poorer health status, lower levels of educational attainment, and have inferior employment prospects and outcomes. People with disability are often subject to discrimination and stigmatization, putting them at risk of social and economic exclusion, which impacts their overall wellbeing and quality of life negatively. Links between poverty and disability have been highlighted: it is estimated that 80% of people with disability live in developing countries where there is often less opportunity to improve their circumstances and the likelihood of falling into poverty is increased (House of Commons International Development Committee, 2014). The vulnerability of people with disability has been recognised internationally and addressed through the implementation of programs and policies focussed on facilitating disability-inclusive development (House of Commons International Development Committee, 2014; Ministry of Education and Sport, 2010).

Lao PDR has a population of about 6.5 million people (Lao Statistics Bureau, 2015) and in spite of economic growth at an average of 8% in 2012 (Cooper, 2014), there are still major development challenges to be overcome. This project has focused on identifying barriers and facilitators to access to essential services for people with disability, which prevent them from being able to participate fully in Lao society.

Implementing the UNCRPD

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets out a human rights framework. In 2008, the Lao Government signed the UNCRPD, and ratified this decision in 2009.

> The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (UNCRPD, Article 1).

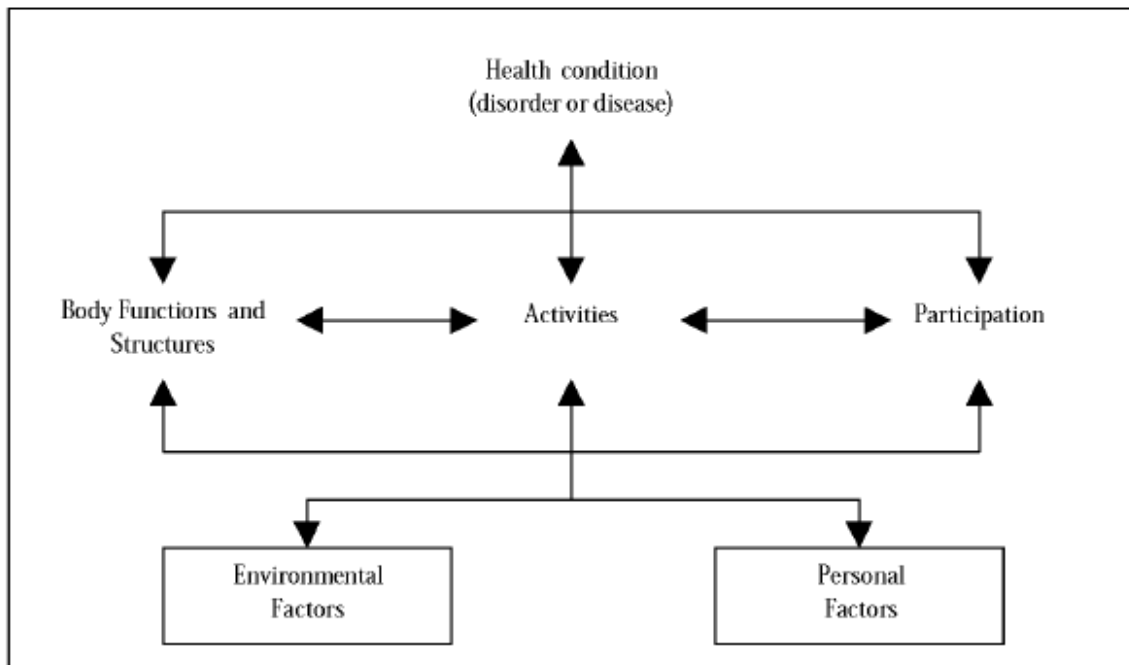Following this, the Lao Government issued the Decree on the Rights of Persons with Disabilities (2014) to:

- Protect the rights and interests of persons with disability.
- Formulate policies on treatment, health rehabilitation, vocational training, employment promotion and other policies, which aim to promote self-development and self-reliance of people with disability.
- Eliminate all forms of discrimination against people with disability, in order to create conditions for people with disability to participate fully and on equal basis in social activities.

Meaning and Identification of Disability

The identification of disability is complex, dynamic, multidimensional, and contested, and there is no agreed international standard to measure it (Mitra, Posarac, & Vick, 2011). The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO) in 2001 integrates medical and social models of disability (WHO, 2001).

This project has used the ICF conceptual framework proposed by the WHO. The ICF is based on an understanding that disability is an umbrella term, which reflects the interaction between a health condition, impairments of body structures and functions, activity limitations and participation restrictions, which are affected by environmental and personal contextual factors (WHO & The

World Bank, 2011). This conceptual framework requires both a medical understanding of a health condition and impairments of the body, and a social understanding of the impact of the environment in terms of barriers and facilitators to participation in everyday life.

Health condition
(disorder or disease)

Body Functions and Structures

Activities

Participation

Environmental Factors

Personal Factors

The ICF (Reprinted from WHO, 2001: p. 18)[1]

Disability-Inclusive Development

The UNCRPD has provided a sound basis to advocate for the rights and full citizenship of people with disability and has, in many instances, facilitated the development and implementation of laws, policies, and practices to provide improved support and services for people with disability.

The increased emphasis on disability-inclusive development across the region and internationally (Australian Government, 2008; Australian Government, 2015; United Nations Economic and Social Commission for Asia and the Pacific, 2012) has enabled substantial progress over the past decade. These international disability-inclusive development frameworks have established a foundation for DPOs and other advocates to lobby governments to improve the rights and access to services for people with disability. For countries in the region, this provides important leverage to ensure that people with disability, as some of the most disadvantaged in society, are included in development strategies. One of the key features of disability-inclusive development is that its focus is intended to benefit the whole of society and has been a theme in high-level meetings of the UN General Assembly from 2006 to 2015 (United Nations General Assembly, 2015).

The Australian Government's strategies from 2009-2020 introduced a number of initiatives which have now been operationalised to support and progress disability-inclusive development. The Australian Strategy is premised on a commitment to implement the UNCRPD and provide opportunities for people with disability to develop leadership skills. These are identified as necessary

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[1] The authors have obtained permission to reproduce this diagram from the WHO, available from http://apps.who.int/iris/handle/10665/42407 (last accessed 17 January 2017).

precursors to 'promote a whole of government approach to disability inclusion through coordinating and mainstreaming efforts across partner government departments and service providers' (Australian Government 2015, p. 16). Achieving this whole of government approach is a major challenge for governments across the world.

Meaning of Social Inclusion

Social inclusion is not simply the opposite of social exclusion. Social exclusion is a process driven by unequal power relationships, which create divisions across economic, political, social and cultural dimensions. It denies access to resources, rights and services and prevents participation in normal relationships. It affects the quality of life of individuals and the equity and cohesion of society (Taket, Crisp, Nevill, Lamaro, Graham and Barter-Godfrey, 2009).

Social inclusion should encompass processes that aim to ensure that everyone, regardless of life experiences, can achieve their potential as active and productive citizens. Social inclusion as a process can be measured against specified indicators, for example, improved educational achievement, improved employment prospects, and improved health. In addition, when capacity building is linked to indicators of social inclusion, there is the potential to improve accessibility to social and economic activities for all. This results in a fairer society. In order to achieve this, the voices and lived experience of people with disability must be included in planning processes and service delivery. It is only then that social change is possible and political, social and economic participation can follow, such that people with disability can be full and active citizens.

Starting with an understanding of disability as a construction of impairment, function and the social environment, the UNCRPD introduced the principle of 'reasonable accommodation'. 'Reasonable accommodation' refers to the necessary and appropriate adjustments to ensure people with disability can exercise their human rights and freedoms on an equal basis with others, while not imposing a disproportionate burden. Social inclusion reflects ongoing tensions in society about how to achieve both social justice and social order (Stewart, 2000). As we look at social inclusion, we need to ask ourselves questions about our values, a range of strategies for social change, and whose needs are more important.

Project Activities

The research project was designed with participatory action research principles. All research activities were approved by the Curtin University Human Research Ethics Committee, and included:

- A desktop review of the literature was conducted, discussed with key stakeholders, and presented at a regional disability conference.
- The Reference Group met regularly to guide the researchers, to review the research instruments and progress, to discuss interpretations and challenges, and to find shared meanings.
- A stakeholder mapping survey in Vientiane Capital and in the three selected Provinces provided information about the existing relationships between key stakeholders.
- Capacity building activities occurred throughout the project and included a 5-day M&E workshop for 35 participants, 2-day training for the survey data collection for 25 people, 2-day data entry training for 10 people, 3-day qualitative data collection training for 5 people, and a one month Australian Award Fellowship (AAF) program for 15 future disability leaders in Australia.
- The Curtin research team and LDPA co-researchers collected qualitative information over two years, using a variety of methods to gather in-depth and contextual information from people with disability, Village and District authorities, and key stakeholders in Vientiane Capital. These included individual interviews, focus groups, participant observation, open-ended survey questions, consultations and site visits. Reflective discussions with key stakeholders, including the Reference Group, allowed for review at each stage
- A survey of households in three Provinces used the Washington Group short set of six questions on disability (Washington Group, n.d.), supplemented by questions about local context. The survey involved LDPA Provincial Coordinators; Provincial, District, and Village officials and volunteers; and survey enumerators, who were recruited through LDPA, MOLSW, Ministry Of Health (MOH), and Ministry Of Education and Sports (MOES). The survey was conducted in late 2015 to identify barriers and facilitators to health, education and employment services for people with disability in Vientiane, Savannakhet and Sayaboury Provinces. Within each Province, two Districts were selected and, then within each District, two Villages. The survey was designed in two stages: a screening questionnaire for all current residents of the selected Villages to assess the level of disability using both the Washington Group short set of six questions and a self-identifying question. In the second stage, a random selection procedure was applied to select respondents with and without disability for a longer questionnaire. Analysis of people with disability was compared to people without disability. Additionally, Village leaders and District officials responded to a survey about demographics and services.
- The Curtin team and LDPA co-researchers constructed case studies to explore challenges and successes in disability-inclusive practices, related to health, education and employment. These included illustrations of leadership, overcoming obstacles, and working collaboratively.
- A 2-day disability-inclusive workshop presented the findings in Vientiane Capital in September 2016 to 60 key stakeholders, and their reflections and discussions provided valuable feedback. The outcomes and recommendations from that workshop have been synthesised for the final policy implementation workshop in Vientiane Capital in February 2017, for 60 key stakeholders, to assist policy-makers with their task of designing and implementing disability-inclusive policies and programs.

Policies for Disability-Inclusive Development

In the past, development policies and programs have not necessarily benefitted people with disability (Australian Government, 2008), despite the bi-directional causal effect between disability and poverty: disability causes poverty and poverty causes disability (WHO & The World Bank, 2011). While people with disability are among the most vulnerable and excluded groups in the world, the Millennium Development Goals (MDGs) (2000-2015) failed to make specific mention of disability or include targets for people with disability (Thomas, 2005). The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), following the first Decade of Disabled Persons (1993-2002)[2], developed a regional framework for the second Decade of Disabled Persons (2003-2012) which incorporated targets for people with disability within the MDGs framework (United Nations Economic and Social Council, 2003). This became known as the Biwako Millennium Framework. The third Decade of Disabled Persons (2013-2022), also referred to as the Incheon Strategy, 'aims to accelerate disability-inclusive development and UNCRPD ratification and implementation' and includes 10 goals to "make the right real" UNESCAP, 2012). The Sustainable Development Goals (SDGs) (2016-2030), which have replaced the MDGs as the predominant international development framework, form a disability-inclusive framework (United Nations General Assembly, 2015).

Throughout the international community, particularly in Asia and the Pacific, there have been concerted efforts to pursue disability-inclusive development. The Australian Government has committed to taking a leadership role in disability-inclusive development internationally and has deployed a 'twin-track approach' of 'mainstreaming' and 'targeting' disability (Australian Government, 2015). This means 'actively including people with disabilities as participants and beneficiaries of development efforts across all sectors' and 'targeting people with disabilities in development initiatives designed specifically to benefit people with disabilities' (Australian Government, 2015, p. 12). However, this is only possible when good information about people with disability is collected: 'To make people count, we have to count people right' (WHO & UNESCAP, 2008, ii). This is why compiling disability information is an integral part of the UNCRPD (United Nations General Assembly, 2006), Incheon Strategy (UNESCAP, 2012), and Decree on Persons with Disabilities in Lao PDR (Lao People's Democratic Republic, 2014).

Findings

The synthesised findings presented below draw on the full range of desktop, quantitative, and qualitative research and project activities outlined in the Project Activities section.

Disability information

There is limited disability information available for Lao PDR, with historic assessments based on self-identification and impairments suggesting very low prevalence rates: 0.7-1.0% in 1996 and 1.3% in 2005 (Thoresen, Fielding, Gillieatt, & Campbell, 2014). However, secondary analysis of the World Health Survey (2002-2004) using an expanded measure of disability based on functioning generated a high estimate of 12.7% (and low estimate of 3.1%) (Mitra, Posarac, & Vick, 2011). There was a shift

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[2] The Asian and Pacific Decade of Disabled Persons (1993-2002) sought to expand opportunities for 'full participation of people with disabilities in society and their equality in the development process' (Price & Takamine, 2003:116). It followed the United Nations Decade of Disabled Persons (1983-1992) which aimed to prevent disability, and improve 'rehabilitation and the full participation and equality of persons with disabilities' (Price & Takamine, 2003:116). The United Nations International Year of Disabled Persons (1981) and the World Program of Action Concerning Disabled Persons (1982) preceded the United Nations Decade of Disabled Persons.

from impairments to function in the conceptualisation of disability in the fourth Lao Population and Housing Census. In 2015, 2.8% of the population had disability (1.9% mild, 0.6% moderate, and 0.3% severe functional limitations) (Lao Statistics Bureau, 2016) across the six domains of Washington Group Short Set of Questions (Washington Group, n.d.). There were no differences in the prevalence or severity of disability between the genders, but differences were observed with regards to location: the lowest prevalence was in urban areas (2.5%) followed by rural areas with roads (2.9%), with the highest prevalence in rural areas without roads (3.3%). Savannakhet was the Province with the lowest prevalence (1.9%), while Xaysomboun was the Province with the highest prevalence (4.0%). The prevalence increased markedly with age, reaching almost one in five among persons aged 60 years or older (18.4%) (Lao Statistics Bureau, 2016).

This project identified the disability prevalence in three Provinces through a household screening survey as well as in-depth information about differences in socioeconomic characteristics between people with and without disability though individual surveys. The screening survey suggested a much higher disability prevalence rate (10.8%) than the 2015 Census (2.8%), although these figures are not directly comparable due to different methodologies[3]. The project identified similar demographic trends as the Census and has reported the disparate socioeconomic characteristics between people with and without disability (Fielding, Thoresen, Gillieatt, Nguyen, & Blundell, 2016).

Mainstreaming disability

Despite some programs having committed to this, the project identified limited, albeit growing, evidence to show that disability-inclusive development had become mainstream across development efforts in Lao PDR. For example, although stakeholder organisations in the stakeholder survey were predominantly disability-specific organisations, very few identified non-disability specific stakeholders among their collaborators. There were two notable exceptions which were both elaborated on in the September 2016 Workshop (Fielding et al., 2016):

- Inclusive Education – which has a relatively extensive track record in Lao PDR (Thoresen et al., 2014) and is spearheaded by the Inclusive Education Centre (IEC), MOES.

- Employment – with Digital Data Divide providing vocational rehabilitation and employment pathways for people from disadvantaged groups, including people with disability.

Targeting disability

The majority of programs identified by the project were disability-specific, as were most of the collaborators identified in the stakeholder survey. Numerous targeted projects and initiatives related to advocacy, livelihood, education and training, employment, and medical rehabilitation, were identified among the Lao PDR disability stakeholders (including Government Ministries, DPOs, NGOs, and INGOs). The following examples are those that were reported in the September 2016 Workshop (Fielding et al., 2016):

- Access to employment – specifically in Savannakhet Province as a collaboration between Handicap International (HI) and LDPA Savannakhet.

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[3] People with disability identified through the screening survey were those who had moderate or severe functional limitations or who self-identified through a direct question. The disability prevalence in the screening survey was 25.8% if using the same approach as the 2015 Population and Household Census (at least 'some difficulty' in at least one of the six Washington Group questions), which is more than nine times the 2.8% prevalence rate from the Census.

- Medical Rehabilitation – specifically in Sayaboury Province as a collaboration between Centre for Medical Rehabilitation (CMR) and LDPA Sayaboury.

- Early intervention and education support – specifically for children with autism by the Association for Autism (AfA) at the Centre for Autism.

- Vocational Rehabilitation – specifically for women with disability provided by the Lao Disabled Women's Development Centre (LDWDC).

- Leadership – specifically at Village and Village Unit level in Vientiane Province provided by LDPA Vientiane Province. An outcome of a HI-LDPA initiative several years ago.

Recommendations

The following recommendations have been synthesised from the discussion and presentations at the September 2016 Workshop, as supported and contextualised by additional information and observations throughout the project:

Disability information

- Access to, and full participation in, education, employment, and healthcare is a challenge for people with disability throughout Lao PDR. There are a number of multiple disadvantages related to gender, remoteness, ethnicity, and complex or high support needs. Improving disability information is crucial for disability-inclusive development. A continuous and concerted effort for the collection and dissemination of disaggregated disability information at national, regional, and local levels is required for targeted and effective policies and programs to improve access to social and economic services for people with disability in Lao PDR.

- People with disability may be discriminated against or excluded from the full range of socioeconomic activities in society. People with disability may also withdraw or exclude themselves from socioeconomic activities (sometimes referred to as self-discrimination or self-stigmatisation). A continuous and concerted effort for the dissemination of and advocacy for the full range of citizen rights for people with disability is required to improve social and economic inclusion of people with disability in Lao PDR.

Mainstreaming disability

- All policies and programs to improve access to social and economic services in Lao PDR need to accommodate people with disability. This may require sub-targets or goals for people with disability and continuous and concerted M&E of its effectiveness.

- Removing barriers for people with disability in accessing social and economic services is not solely a disability issue, for example, providing necessary infrastructure and appropriate transportation, benefits the community more broadly.

Targeting disability

- Redressing the barriers to access and fully participate in education, employment, and healthcare for people with disability requires targeted policies and programs. These should include strategies to mitigate compounding factors such as gender, remoteness, ethnicity, and complex or high support needs. Improving the quality of information about disability is crucial for disability-inclusive development.

Policies for Integration, Rehabilitation Support

Important to both disability-inclusive policies and social inclusion are questions about how to integrate values, principles and practices. First an analysis of power relations in social, political, economic and cultural contexts will show to what extent there is a willingness to change (Taket, Crisp, Graham, Hanna, Goldingay & Wilson, 2014). This is important because the design of policies and services needs to change existing practices which have an exclusionary outcome. People with disability often face additional health challenges, and a higher risk of poverty. The ADRAS funded survey found people with disability have significantly poorer health than people without disability, and a very low proportion of women with disability are covered by any form of health insurance or protection in spite of their greater need (Fielding et al., 2016). To improve access to education and employment, it is necessary to integrate health and rehabilitation support with education and employment.

Approaches

Inclusive Service Designs

Inclusion in service design means service users and service providers working together in making decisions, providing support and encouragement through support groups. In specific services, Taket et al (2014) found that social inclusion is stronger in services, when service users and families are members of active advocacy groups, and can provide advocacy, advice and input. Similarly, where services have inclusive environments using universal design, all service users can access the services and feel welcome.

People with disability would naturally be a part of the workforce in an inclusive organisation, and would provide training and education for other service users and service providers (Taket et al., 2014). Practising social inclusion in community life needs a community development approach, development of partnerships, and people with disability are involved in meaningful participation (Stewart, 2000). Community self-help means that people with disability are part of the governance structures at the community level. To achieve this, there is a need for better integration of services for people with disability.

Service Integration

Service integration is a term being used to describe a means of breaking down barriers between organisations and within organisations so as to avoid wasting resources, to fill service gaps and to overcome resistance to change (Moran, 2013). The promises of service integration are a greater focus on the problems citizens identify, better coordination of activities, and the creation of new opportunities to share information across organisational boundaries. Each organisation contributes from its area of expertise so that holistic services can be planned and delivered where they are needed in an efficient manner. Moves in this direction need action plans and M&E plans.

The discussion among key stakeholders at the September workshop identified some challenges for integration of policies and services in Lao PDR. The following section is a synthesis of de-identified points raised during discussions. They are summarised under the following headings: Knowledge and Information, Access to Health Services, An Integrated Approach, Building Capacity in Disability Organisations.

Knowledge and Information

- The process of drafting the Decree on People with Disability was lengthy (2007 to 2014). At first there was little understanding of disability among policy makers, people with disability

were not involved, and people with disability had little knowledge about international policies or conventions or about their rights. There was hesitation because so much was unknown. International experts provided support, the Government worked with DPOs and with encouragement, information and financial support of INGOs, the process led to stronger connections, both technical and personal, between Government, DPOs, and INGOs. The Convention has been ratified, it has become a very important tool to protect the rights and uphold the dignity of people with disability.

- An HI project to identify barriers for community members to access services found that people with disability lacked information about important services, which could help with access to employment.

- Although a particular service provided free accommodation, people with disability and their families could not pay for the travel or food. Assistive devices were scarce, and the Centre advertised its services to people who were very poor, and not specifically to people with disability.

- People with disability need information about different policies to help them access public services. People in remote communities need rehabilitation services. Families and community need information to provide care and treatment, and to support people with disability to be self-sufficient.

- In rural areas, there is still little information about health conditions or rehabilitation, education or employment support for people with disability. There is also mis-information among some health professionals. Sometimes there is a commitment to provide more resources but the budget does not match. On other occasions, there is a problem interpreting policy and implementing it in practice.

- The community provides an important enabling environment where people with disability, family and society focus on the interests of people with disability for education and prepare them for employment. We need to improve access to health and education for people with disability. The infrastructure means it is difficult to access health care centres and schools. We must involve everyone in society, parents, village and community.

Access to Health Services

- The laws on social welfare insurance are being reviewed so that vulnerable and low-income people can get access. The existing health insurance schemes are complex, and are being improved to make it possible for people with disability to access treatment. People with a disability should have a health insurance card, which will give them access to free services such as a general health check or treatment plan.

- Disability may include mental health problems as well as physical impairments. All people with disability including mental health issues and intellectual disability need access to basic care, treatment and rehabilitation.

- We need to provide information to communities to support the health of people with disability. We need to provide equipment and assistive devices, and support for travel to health services.

- Poor roads and infrastructure also make it difficult for the mobile clinics to reach remote villages.

An Integrated Approach to Education of Children with Disability

- For children with disability, early intervention requires integration between the health and education systems. A diagnosis is needed in order to plan support for the child with disability in the school environment. Assistive devices, study materials and an accessible building all

require integration of services. Some conditions such as autism are difficult to diagnose. Inclusive education requires more educators with specialist skills. Targeted services for children with disability are very limited.

- Parents and teachers need support and information. Parents and teachers must also support the children according to their strengths. The family needs to teach the child with disability and provide encouragement to support their educational needs and goals.
- Integration of rehabilitation support is crucial for children with impairments to participate in education and for adults with impairments to participate in employment. Health, education and employment are integrally linked.

Building Capacity in Disability Organisations

- Families and society should give people with disability the opportunity to demonstrate their capacity. If we look at their disability only, their capacity will be ignored. We should study the existing capacity of people with disability. This will help with employment of people with disability at various levels.
- The impact of not educating people with disability and training for employment is poverty.
- Disability organisations promote the value of people with disability, not disability itself. The challenge is to change attitudes, reduce stigma and expand resources. We have to think about how we can expand the work of DPOs.
- It is important to learn about and understand what jobs people with disability can do, and support them to do them. It is important to recognise the courage of people with disability, who feel vulnerable and lack confidence. People with disability, employers, families and the community need information that will encourage training and employment opportunities for people with disability.

Summary of Recommendations

- People with disability need to know their rights. Service providers and employers need to know their obligations to protect the rights of people with disability.
- Information about health services, and access to health services need to be improved. People with disability need free health insurance and access to basic health care and rehabilitation.
- A longer-term view needs to be taken to improve road access to remote areas.
- Early intervention requires an integrated approach by the Ministries of Health and Education. Parents need to be educated to support their children to access early intervention programs and attend school.
- Disability organisations can help to reduce the stigma of disability, and encourage people with disability and their families to acknowledge the capacity of people with disability.
- Disability organisations need to be supported to do this work.

Policies for Capacity Building

Background

Capacity building and capacity development have their roots in "community development, international aid and development, public health and education" (Crisp, Swerissen and Duckett, 2000, p. 99). Indeed, there is a variety of operational definitions, and stakeholders in different countries and contexts define these concepts differently.

For the Organisation for Economic Co-operation and Development (OECD), capacity building is about developing skills, experience, and technical, and management capacity within an organisational structure (OECD, 2002) and capacity development is the process by which individuals, groups and organisations strengthen their systems, resources and knowledge (OECD, 2007). According to Simister and Smith (2010), capacity building can be many things: that is, technical or general capacity, for example, capacity for people with disability, capacity for people working in disability or capacity for all, as well as a capacity as a means to an end or as an end in itself.

Both capacity building and capacity development are difficult concepts and only make sense when localised to a specific context. The question then becomes: capacity building and capacity development of what type and for whom in Lao PDR?

Approaches to Capacity Building

Crisp, Swerrisen and Duckett (2000) describe four approaches to capacity building. The disability sector in Lao PDR recognises the need to build capacity and indeed all four approaches are relevant to Lao PDR. They are:

- Top-Down where the focus is on changing institutional/organisational structures and policy which in turn facilitate awareness, learning, change and ultimately improved responsiveness and capacity, for example, the Lao Government's Decree on Persons with Disability (2014) and the MOES' National Policy on Inclusive Education (2010).
- Community-Organising of disenfranchised members of a community who grow ambitious, transformative disability networks led by people with disability or led by the parents/ family of children with disability, for example, LDWDC, and AfA.
- Bottom-Up which can involve the provision of training for people in organisations who then share their skills and knowledge with others. This works best when organisations are committed to continuous learning and improvement, for example, LDPA and its partnerships with HI and World Education leads training in disability awareness.
- Partnerships through developing new partnerships and strengthening existing partnerships between organisations which may have had limited working relationships in the past. The focus here is on strengthening cooperation and establishing and enhancing two-way flow of knowledge and skills, for example, ADRAS-funded Lao project survey, the invitation from the MLSW to conduct M&E training and the invitation by the Lao Statistics Bureau to conduct disability training.

In relation to the ADRAS-funded Lao project, the capacity building and capacity development aspects were about developing technical skills and disability knowledge in Lao disability stakeholders for disability-inclusive practice and the conduct of disability-specific research and M&E in Lao PDR. Importantly, the first step in building capacity was to undertake disability stakeholder mapping in Lao PDR to identify the key stakeholders as well as their activities in supporting people with disability. This assisted in building a comprehensive picture of key disability stakeholders,

stakeholders who would then become the focus for capacity-building around collecting, analysing and using disability information. The training for research (research planning and logistics, quantitative and qualitative data collection and entry) and M&E (systems, data, and M&E plans in inclusive health and rehabilitation, inclusive education and vocational training, employment and vulnerable populations) was underpinned by the principles of good disability-inclusive development practice. These principles included customising approaches to the local context, incorporating a rights-based approach, recognising the essential participation by people with disability, recognising that intersecting forms of exclusion exist, and promoting a focus on reasonable accommodation and universal accessibility (Plan International Australia & CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, 2015).

Our learning from the last three years, including observation and recording changes, indicates that:
- The network of disability stakeholders has both expanded and strengthened within and between levels
- The participation of people with disability has been recognised and accepted as crucial
- People with disability have grown in confidence, and
- The technical skills and knowledge of both people with and without disability in disability research and M&E have grown.

Recommendations from September 2016 Workshop
Key points about capacity building were made at the September 2016 Workshop. These include:

- The capacity of people with disability is often overlooked
- Capacity building through mutual partnership is effective
- Capacity building will be further enhanced as coordination between the health, education and employment sectors grows
- Relatively recent inclusion of the Lao Women's Union as a key stakeholder in the disability sector in Lao PDR
- Lao PDR may consider developing a detailed analysis of future capacity needs for technical, disability-specific (disability sector) and disability-inclusive practice (broader society to gain greater knowledge of disability)

Finally, the engagement of 15 Lao disability leaders in the AAF Program (September 2016 – February 2017) has contributed to the capacity in the disability field by developing and strengthening leadership, and establishing new networks, to counteract the inevitable losses of key personnel in disability in Lao PDR. A general question posed by Kotvojs and Hurworth (2009) remains relevant to Lao PDR: what changes have happened as a result of capacity building in disability-inclusive development in Lao PDR?

Policies for Coordination and Service Integration

These recommendations are synthesised from the research findings and existing literature on service coordination and service integration, and are grouped under headings: the importance of coordination, existing problems with coordination and examples of coordination at work. Finally, the concept of service integration is examined as a framework to improve coordination in Lao PDR.

Importance of Coordination

Throughout the research project, coordination was identified as very important. The NCDE holds responsibility for developing a national strategy and action plan in line with the National Decree. There has been much discussion about the importance of policy dialogue between MOH, MOES, MOLSW and the Ministry of Public Works and Transport (MPWT) as well as a coordination mechanism to implement agreed policies and programs.

Comments from key stakeholders at the workshop demonstrate a commitment in Lao PDR to a coordinated approach. Suggestions from participants include:

- At national coordination level, a percentage of GPD, maybe 1%, should be allocated to support people with disability. People with disability are often excluded from health funds. Recommend policy for treatment of people with disability, including a health concession card, which reflects the nature of the disability. Training for all health staff from the centre down to local levels would mean that people with disability could have access to rehabilitation and basic orthotics at the local level. All services need to be accessible, non-discriminatory and friendly to people with disability.
- External funders need to coordinate and cooperate too.
- Local authorities need to take ownership and actively support families.
- We need to make plans for local levels, including villages, districts, and the provinces. People with disability must be involved in the plans and initiatives. They must participate when research and M&E is conducted in the villages. We must use the NCDE for coordination.
- We need a plan for building capacity for people with disability and an action plan for the activities in Lao PDR

Existing Problems with Coordination

> Accessibility is a pre-condition for independent life and full and equal participation of persons with disabilities in society. Without access to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, persons with disabilities would not have equal opportunities for participation in their respective societies (UNCRPD Article 3 f).

The World Report on Disability (WHO & The World Bank, 2011, p. 10) stresses that built environment, transport and information and communication are often inaccessible to people with disability. When this is the case, people with disability are prevented from enjoying their basic rights, like the right to seek employment or the right to health care, due to lack of accessible transport.

Feedback throughout the project made reference to confusing and conflicting policies relating to eligibility for education, pensions, and health care for people with disability:

- Lao PDR has been reliant on funding from many donors, each with their own ideas and expectations for short term projects. This makes coordination a challenge.

- Even when people with disability are given wheelchairs and prosthetics, they cannot get the necessary rehabilitation because transport to the rehabilitation centre is too difficult.
- Barriers exist in the form of inaccessible buildings, transport, toilets.
- What is needed is policy to ensure people with disability have equal opportunities as others to health, education and employment. People need to pay attention to the needs of people with disability and to address the stigma faced by people with disability.

Several comments referred to the impact of the challenges of coordination. Advocacy groups have identified lack of coordination and have had to find alternative means of coordination. For example,

- Lack of coordination between UNCRPD, Decree on Disability and between Ministry and District levels of Education resulted in parents of children with specific conditions having to negotiate at each step of their child's development to have the children included in school classrooms.
- The community is important as an enabling environment where people with disability, family and society focus on the interests of people with disability for education and prepare them for employment. The infrastructure means it is difficult to access health care centres and schools. First we need good statistics in order to make plans. We must involve everyone in society; parents, villages and community.
- Even when people need support, they do not necessarily know how to communicate or where to get that support. Even though some services are free, sometimes neither people with disability nor staff know this. People with disability and their family are afraid of the costs, and staff give them wrong information.

Examples of Coordination at Work
- Increasing public awareness helps people with disability to have the opportunity to participate in social activities
- Step by step barrier assessment (HI project) starts with awareness-raising and role clarification. Then, key services needed by people with disability are identified and ranked. Action plans are followed with M&E. The collection of good practices is then shared with decision-makers and policy-makers.
- LDWDC receives funding from several sources to provide job training for women with disability. With support from World Education, they are revising the curriculum to meet MOES standards, and to ensure graduates have vocational skills and a recognised certificate.
- The IEC is gathering information about the number of children with disability who are attending school. The reports are varied without a standardised method of data collection. The IEC is working with the Australian Embassy to select and pilot the best available data collection form, before implementing a national data collection.

Key features of good coordination, identified in the literature and in the research findings, include:

Legal and Administrative Framework
- The Decree needs to become law to ensure and protect the rights of persons with disability as citizens.
- The need for good disability data, and a commitment to disaggregating the data.
- A commitment to combat inequalities and discrimination.
- A strong accountability framework at all levels, including M&E of policies and services.
- Inclusion of people with disability at all levels of planning, decision-making and service delivery.

Organisational Planning and Procedures
- Planning and coordinating responsive services.
- Service integration to provide support and ensure full participation of people with disability.
- Training for staff to overcome discriminatory practices.

Community, Family, Individual
- Identifying needs at community and family level.
- Recognition of strengths and abilities of people with disability.
- Learning about the impact of impairments and discriminatory practices.
- Valuing and supporting self-reliance.
- Providing support to remove barriers and maximise each person's abilities.
- Information about available services.

Need for both vertical and horizontal integration

Policy and planning at a national level require an inclusive whole of government approach. The NCDE is responsible for coordinating a national strategy and action plan on disability. This task requires the MOLSW, MOH, MOES, MPWT, and other Ministries as required, to work with the LDPA, other DPOs, and INGOs.

Vertical integration involves connecting this process to the Provincial, District and Village levels through Ministries to their respective Departments in the government group, and through LDPA and DPOs. It would be beneficial to include the mass organisations, such as the Lao Women's Union and the Lao People's Revolutionary Youth Union, who have existing vertical integration processes.

Horizontal integration means that at Village and District level, there are opportunities to raise awareness about disability across the local community and to provide support to people with disability and their families, to provide information about entitlements to health, protection, education and employment, to identify needs of people with disability, and to provide this information to province level. At the national level, the NCDE can monitor the delivery of services and respond to evaluation feedback at each level.

To do this effectively, all partners need to share information about data they collect, and services they deliver. It would be helpful if international funders were to coordinate their funding programs to enhance the national strategy. At Province and District level, it is important to coordinate and integrate service delivery, ensuring that local policies and practices are aligned with national policy and with the needs of local people. These feedback loops provide a more integrated process. National specialist services have the responsibility to deliver their services to meet the needs of people with disability throughout the country. The private sector also needs to be involved.

Local leaders need additional training and guidance to deliver primary care and rehabilitation services in villages and communities. People with disability may need advocacy training and the DPO sector needs to be strengthened. The nature of the services and the skills of the professionals/service providers and volunteers at each site need to be carefully assessed and monitored. Developing the community based rehabilitation (CBR) model could be useful for this approach.

Recommendations

An integrated approach requires a shared understanding of the meaning of disability (for example, the ICF), shared commitment to principles of inclusion and non-discrimination, and a legal

framework to ensure people with disability share equal rights as citizens of Lao PDR. Inclusion of people with disability in all stages of coordination and planning is very important to the process.

A coordinated strategy and action plan needs both horizontal and vertical integration.

Expanding the network to include the mass organisations could increase both horizontal and vertical integration, demonstrating that addressing the challenges of disability is everybody's business.

These changes may challenge existing ways of working, but they can enhance existing governance arrangements, and benefit the whole community.

Concluding Remarks

While the recommendations and challenges identified in this Report are many, it is the Curtin team's observation that Lao PDR has made significant steps in collecting disability information and mainstreaming and targeting disability since the Decree came into being. These advances have occurred against the backdrop of observable increases in the capacity of Lao disability-specific, health, employment and education sectors in the areas of disability awareness and knowledge, disability leadership, and research and M&E knowledge and skills for disability. Lao leaders including people with disability have kick started this critical endeavour for their country and it is these leaders who have afforded the Curtin team the opportunity to partner and collaborate with both the MOLSW and LDPA on this project. As a group of five Australian researchers, we have learned so much from you. As we wind up this project, we are mindful that the next challenge will be for new and emerging disability leaders to maintain and further this wonderful momentum.

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